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ABSTRACT

The manual offers a process and suggestions to help support groups working to make disabled individuals less dependent on professional recreationists and segregated programs. The manual is divided into 10 steps and can be completed in a 1-day meeting or over a period of weekly meetings. Step 1 focuses on leisure, what it is and how it happens. Step 2 helps the group to establish goals for the future with the supported person. Step 3 takes the group through the difficulties possibly encountered in achieving the goal; Steps 4, 5, and 6 all examine aspects of the connections between friendship and leisure. Step 7 focuses on a plan which allows for the individual's needs, strengths, gifts and desires. Step 8 takes the group from planning to action, while Step 9 looks at the group's own future roles and directions. The final step, 10, is a concluding exercise and considers ramifications of achieving the plan. The book ends with a number of resource lists. Includes 8 references. (DB)

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LEISURE

ENABLING PEOPLE WITH A DISABILITY TO LEAD RICHER LIVES IN THE COMMUNITY.

EC 300692

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FOREWORD

More than three million Canadians have disabilities, and most have more than one. They tend to cite physical disability as the main cause limiting their activities related to work, leisure, and recreation. In fact, most are not leading physically active lifestyles, with nearly half never participating in physical activity at all.

Certainly many adults with disabilities do find ways to participate regularly outside of their homes. But how actively and regularly they are able to do so with non-family members is doubtful. A large majority live with immediate or extended family members, experience serious problems regarding personal, public, and specialized transportation, and so naturally spend a great deal of time within the family orbit. As well, large numbers of individuals find themselves segregated for many hours of the week in their homes watching television rather than participating actively with others in the community.

Such challenges in the area of leisure and recreation for people with mental handicaps and their families are compounded by economics. Large numbers of adults with disabilities are unemployed. Most draw incomes of less than $15,000 per year, and few have any form of disability-related income.

Leisure Connections provides ways to address challenges like these, simply and practically. It was prepared with a clear understanding that people with disabilities often enjoy participating with others in leisure and recreational experiences in the community, and that they indeed often do want to participate more actively. It also recognizes and enables planning around barriers, above and beyond the disabilities that need to be overcome for this to happen. These barriers include how, why, and where to connect with others, what to do about the cost of participation, how to identify acceptable leisure options, and how to distribute more equitably the sometimes all-consuming demands that our society places on family members.

Leisure Connections accepts that family and friends do and will continue to play a critical role in the area of leisure for people with disabilities. Accordingly, it offers a process and some concrete ideas that we hope will empower support groups, by making their role a little easier and by enabling them to become less dependent on professional recreationists and segregated programs.

The exercises provided in this manual have been well received by a number of groups during "field testing" in workshops across the country. While each of the exercises has been modified in light of the feedback we have received, this is the first time they have been offered together as a complete "package." Accordingly, The Institute would be interested in receiving comments on this leisure support process as a whole. Support

groups are also encouraged to use the book as they see fit, either using it "as is" or adapting it to suit their own needs and style.

Apart from the invaluable contributions of Deborah Gold throughout the development and writing of this book, a number of other people participated as well. Among them, Barb Goode and Trish Salisbury offered much insight and many constructive criticisms. Michael Bach, Shelly Butler, and Wanda Taylor also made important contributions to the manuscript in its final stages.

Finally, The Institute gratefully acknowledges the financial assistance of Fitness and Amateur Sport Canada in enabling us to develop and publish this book.

Cameron Crawford
Assistant Director

INTRODUCTION

Overview

Typically, the leisure needs of people with disabilities have not been met to the same extent as for other citizens. There are many reasons for this fact, from poverty (Sylvester, 1987) to segregation (Worth, 1988). But the bottom line is that people with disabilities have been kept from those experiences and activities that make it possible to make and keep friends. Limited contact with people in regular settings has restricted the ability of individuals to develop their leisure interests, desires, likes, dislikes, and gifts. Most important, this segregation and social isolation has *increased* people's handicaps because it has kept typical citizens from coming to know and appreciate them. Essentially, if you've never had the chance to try something, and you don't have anyone to be with you when you do, you will be left with an impoverished life — one that is missing all the rich experiences of those who have friends.

Leisure means that we have the freedom to choose what we want to do, who we want to be with to do it, where, when, and how. It also involves creativity, being completely absorbed in the moment, and intimacy. This last — the desire to be with another person in a particular leisure activity — appears to be the most important aspect of leisure to the majority of people, whether labelled or not (Gunn, 1982). There is evidence in the literature that supports the notion that association and relationships are an important aspect of the leisure experience. In one study of 220 people, it was found that over 93 percent of the participants stated that being with another person was one of the five most important aspects of their leisure (Ibid., 1982, p.20).

What is this book about?

Why do we want to take the time to write about leisure and relationships? Many, many people today are dissatisfied with their lives, and this includes people with disabilities. Overwork, depression, back aches, headaches, ulcers, bad memories, tense shoulders, pressure, over- or under-weight problems are all symptoms of lives that are less meaningful and satisfying than they could be. Many people with and without handicaps want more joy, peace, better health, good relationships, fun, free time, love, support, and friendship in their lives. It is for this reason, more than any other, that we need to think about the importance and

power of leisure for physical, intellectual, spiritual, and emotional well-being.

All people are happier when they have someone in their lives who cares about them. People are sad when they are lonely, isolated, and separated from others — that is, when they are "unconnected." If we can help people with handicaps to overcome the often constant movement of others in and out of their lives by facilitating peer friendships that will be lasting, then we will certainly increase the likelihood that their leisure will be increasingly filled with meaningful activity.

This book, then, is about an idea: how we might be able to help people lead richer lives by supporting them to "get connected" to groups, associations, and community networks in which they will experience leisure and the relationships that will make that leisure meaningful. There are other important kinds of leisure, including that which is solitary. However, because we are concerned about the social isolation of many people with disabilities, this manual focuses on the kinds of leisure that have a social component — leisure experiences that involve relationships (see Appendix F).

For this reason, a special section on the importance of friendship is included in this book. In leisure, we make and keep friends. It is our relationships with other people that make our recreation and leisure fun. And full participation in the community means participating in activity that is engaging, healthy, and enjoyable. Also, being alone is fun only when we can **choose** it. We know that once we have friends to be with, we will sometimes choose to be by ourselves. But loneliness is not the same as chosen solitude. Many people with disabilities are often left alone, and feel lonely. So, introducing a person to others, and supporting those relationships, could be the very best thing that a support person does for an individual.

This type of support — introducing, inviting, explaining, and including can be called **facilitation**. The word facilitation means "making easier; assisting" (Houghton Mifflin). In leisure, people facilitate for us by coming with us when we join clubs, start a new activity, or enjoy an outing. When our friends introduce us to their friends, or when they invite us to a party, they are facilitating the widening of our networks and the deepening of our leisure. For a person with a disability, this need be no different. It may be, however, that someone who has been very

isolated will need more intense and concentrated facilitation than would someone who has been well connected in her or his community for a long time.

We don't know a lot yet about who the best facilitators are, but we do know that when friendships are supported and encouraged, they are more likely to occur and strengthen. Family, volunteers, and paid staff can play a key role in facilitating leisure through relationships. Because many people with disabilities are without unpaid, freely given friendships, it is crucial to encourage friendships with unpaid peers who receive as much from the relationship as they give. These friendships require positive forms of support such as help using the phone, arranging transportation, writing a letter, not to mention the introducing and inviting mentioned above. People who live in human service settings are often simply not supported in these ways.

This manual, then, is written for anyone who is interested in facilitating or supporting friendships and leisure.

Assumptions

In writing this manual, we have made a few assumptions about who will use it.

1. We are assuming that a support group or circle exists already for the person who wants a richer leisure life. We would urge you to invite caring, unpaid, and committed people into the person's life **before** you begin the process outlined in this manual. We also assume that at least one member (the enabler of the group — see below) is completely committed to the person supported and believes in the person's gifts and inherent human value.

2. The group will have a facilitator or enabler, someone who is outside the person's family or inner circle. Judith Snow, who has written and spoken extensively on support circles, lists the following roles for the enabler:

   > His or her role is to help people talk about what they really want. Using a list generated by the parents, advocate, and/or person needing support, the first step is

to help call together a group of supportive people who are willing to commit themselves to hearing the story and the dream. By the second or third meeting, some will drop out, but several will commit themselves to action, perhaps even suggesting potential new members.

The facilitator (enabler) may be a member of another support circle; a "broker" or "coordinator" who is paid to form such groups; or someone comfortable with the process...Within a short period of time...the circle must develop its own process of deciding when and how to get together.

The facilitator must be able to observe, analyze, interpret, and act on three levels at once. On one level, and of primary importance, he or she must be totally allied with the person requiring support, and intimately familiar with the sorts of problems the person is facing. He or she must be able to look past violent or disruptive behaviour; or the silence, passivity, and confusion born from fear and self-doubt. There must be absolute trust that this circled person is gifted, has a truly human vocation, can be in a relationship with many others, and can grow and learn to offer and express these valuable contributions...

The second aspect of the facilitator's work is that of managing a group process and organizing a new set of commitments. One element is helping circle members learn to decide when and where meetings are held, who should be present, and so forth. This work also involves helping people to relax, listen, and contribute during meetings...Value statements and creative suggestions must be highlighted and positively interpreted. Negative contributions must be respectfully contradicted, or otherwise handled so as to forestall further rejection of the circled individual...

The third function performed by the facilitator is that of being a visionary and a teacher. This role must permeate all activities, as it protects the person needing support from future rejection and causes the group to tolerate this interference with their beliefs and ways...Not only is the facilitator attempting to resolve problems and support one person, but he or she is working to revolutionize the values of the group to the point where the members can value differences before rejection occurs... (Snow, 1989, pp.226-228)

The following is a list of tasks that the group enabler must perform:

(a) Ensure that the group stays involved in the process,understands it, and moves efficiently from one task to the next.

(b) Ensure that each group member's ideas are made public. A way to do this would be to write the thoughts and ideas of group members on flip-chart paper and put them on a wall for everyone to see and use.

(c) Ensure that the individual with a handicap is as involved in the process as possible, and that he/she is receiving support to participate. (No meeting shall take place unless this individual can attend.)

(d) Provide ideas for ways in which to proceed, but most important, allow the group to proceed in its own way and at its own pace.

(e) Begin by reading the manual through twice. It is a good idea to make notes about areas that may need explanation or discussion.

3. We assume that although the support group may be concerned with other issues in the life of the circled person, members of the support group and the person needing support are all using this manual to focus primarily on the leisure and relationship enrichment aspects of life.

4. The group, including the person requiring support, is prepared to struggle with the issues of leisure and friendship facilitation.

5. The entire group is interested both in helping the circled person to discover his or her own gifts, desires, and "likes" and in concentrating on "connecting" to natural networks in the community where friendships have the potential for forming. We assume that in assisting a particular individual, group members will themselves engage in the process, discovering their own gifts, desires, likes, and needs.

6. Our final assumption is that many people who have been socially isolated will need a "connector" — someone who is

well-connected in his or her community who can introduce the labelled person to a network of community members (McKnight, 1987).

Who is the person being supported?

This person will probably be an individual who has been rejected and wounded in the past. He or she might be socially isolated and unsure as to how to "get connected." He or she wants a change—friends, companionship, acceptance, and belonging. Large numbers of people with disabilities continue to lead lonely lives, dependent on a few family members for social and leisure contacts. This manual was written as an attempt to help these people, no matter what their age, no matter what their past experience. If a network or support group exists, this manual may be able to help the group make leisure and friendships a reality. For guidance in developing a group or support circle, please refer to the reference list at the back of this book.

Who should use this manual?

This manual was designed for use by support groups as described above. These groups might consist of important people such as family members, advocates, friends, invited community citizens.

How is the manual organized?

The manual is divided into ten steps. Each step leads to the next, such that Step 1 should be completed before Step 2 and so on. These steps can be completed in the course of a one-day get-together, or over a period of weekly meetings. The steps are most effective when they are done in one or two group meetings, no more. The group is then able to remember the results of the first parts while working on the last.

Step 1 focuses on leisure — what it is and how it happens. Step 2 helps the group to dream about the future with the supported person. Step 3 takes the group through the difficulties there may be in achieving the dream. Steps 4, 5, and 6 all examine aspects

of the connections between friendship and leisure. They ask the group to examine the importance of friendship and how it is connected to leisure. Step 7 focuses on a plan. This plan will be a launching pad for the group and the circled person in social leisure experiences.

Step 7 is not meant to be "stuck to no matter what." It will be a flexible, practical step for the person needing support. That person must remain at the centre of the planning at all times. The support group, and particularly the enabler, will have to remain aware of how the person's needs, strengths, gifts and desires are changing. Step 8 takes the group from planning to action, while Step 9 looks at the group's own future roles and directions. The final step, 10, is entitled "Beyond the Plan." Here, as a concluding exercise, the group is encouraged to think about what will happen as the plan is achieved. At the end of the book are a number of resource lists that are related to some of the exercises. They are included to help the group think as creatively as possible.

About the Manual

This book is a **process**. Creative thinking will be the key to the success of the group's work. The group members, including the supported person will have to remain open, constantly questioning their assumptions about the possibilities in leisure. This openness will allow the process to work at its very best. The word "process" also means that the planning and other work of the group is never really over. Instead, what happens is that, as the person becomes increasingly connected and involved, the group's roles change in response.

This book is also a guide and should only be used as such. Because every group will be different in what its members envision together and what they plan, the manual cannot specifically tell them what to do or how to do it. So, if the questions are felt to be cumbersome or difficult as they are formulated in the book, participants should feel free to depart from the outline. Most important, if people have their own questions that are not outlined here, they should include them in the list.

Individual group members can use the manual to write down personal notes and thoughts. However, a group record should

also be kept. A way to do this is to make notes with coloured felt pens on large pieces of paper that can be posted on the wall as the group proceeds. As well as writing everything down, the group may want to record its sessions for future use as new members join, or to refer to later. The use of a tape recorder should be a group decision, with input from the person in need of support.

Final Comments

Remember that the goal of the manual and support group is to help an individual to lead a richer and more meaningful life. Therefore, every individual's leisure plan will look different from every other individual's. There are no special formulas or quick-fix answers or solutions to questions about people's lives.

References to the "person being supported," the "circled person," and, the "supported person" appear throughout this book. It is important to keep the supported individual at the centre of the planning process. The planning process should only occur with this individual and his or her family and friends. Most important, there should be at least one person present who knows and is trusted by her or him. As suggested above by Judith Snow, this person could be the enabler, but this is not a requirement.

STEP 1. Reflections on Leisure

Purpose: To think about and reflect on the nature of leisure and the role it plays in our lives.

Discussion:

What is leisure? We tend to forget that it is an important part of our life. For instance, when we look at moving, do we think about what the leisure opportunities will be in a particular neighbourhood? It is rare that leisure is considered when someone is moving out of an institution. People often end up living far away from places where other people enjoy leisure, like parks, community centres, streams, theatres, clubs, real neighbourhoods, schools, and so on. Therefore, they miss out on important social and leisure opportunities.

Or we think that people need skills before they can be a part of leisure and we forget that most people learn by doing. It is easier to learn money management by planning and doing a leisure activity than in a "money management class." So all that leisure has to offer is often lost, especially for people with disabilities, who may not have had the chance to say what they want or to make a real choice about where they live or how they become involved.

Or we think about leisure very narrowly: "leisure is sports" or "leisure is fun." But, ultimately, we really don't spend much time thinking about it at all. The following exercises were designed precisely to think about leisure more broadly.*

*Adapted, with permission, from *Leisure: A Resource for Educators*, Ontario Ministry of Culture and Recreation, Toronto, 1978.

All of us need to begin to think about leisure personally. Seldom do we ever take the time to reflect on the meaning of leisure, the role it plays in our lives, societal attitudes towards it, and the ways we generally make sense of it for people with disabilities. So this set of exercises on leisure allows people to do this kind of reflecting alone and together. As you do them, think about what leisure means to you. Have fun!

Notes:

The beauty of this section of the process is that it can be completed before the group meets, alone or with loved ones who are not members of a particular group. These exercises can be completed by the supported person as well, and she or he should be provided with any necessary support to do whatever parts of the process the rest of the group is doing. It is important to understand that the purpose of these exercises is to have all members of a support group come to an understanding of the deep meaning and purpose of leisure in their lives, so that they can support it fully and effectively for others. Thus, as a rule, we do not encourage this kind of "homework." However, it may be necessary in the interest of time.

(a) *What does leisure mean to me?*

Purpose: To help us concentrate on the basic idea of what leisure means to each of us personally.

Instructions:
Write a few words, a couple of phrases, or a few sentences. Use only the space provided. (See Appendix A for statements about the meaning of leisure that other people have made. Try to look at that list only **after** you have filled in the space provided here.)

Leisure to me is:

and

(b) *What does leisure mean to us?*

Purpose: To broaden the group's thinking about the many possibilities in leisure.

Instructions:
After everyone has done the private exercise and thought about their own meaning of leisure, share these ideas with the group, and have someone write all the ideas down on a large sheet of paper. Give the paper the following title: "For our group, leisure is..."

(c) *New ways of seeing leisure*

Purpose: To develop new thoughts about what leisure could be, and to think about leisure's meanings for *this* group. These ideas can be used to broaden everybody's thinking about the possibilities for the circled person.

Instructions:
Each member of the group studies the list that was made up in (b) and chooses one or two ideas that are new and exciting. After each person makes a personal note of them, the group could talk about why and how these are new and different. These could be circled in a different coloured pen as the group talks.

New ideas:

(1)

(2)

(3)

(4)

(d) *What do I need in leisure?*

Purpose: This exercise allows participants to think about their leisure needs, and whether they are meeting them or not. The ways in which people meet their leisure needs may differ, but the needs are the same for many of us.

Instructions:

Check and include the needs that are most important to you in leisure. To have a definition of leisure, look back at the group's list of ideas on the wall. As you go through the list, consider, "What am I looking for in my leisure and recreation?"

When members are finished, the group can then break into partners and discuss why they made the choices they did. The purpose of the discussion is to become aware of how people differ in the choices they make, the things they find important, and what they need most. (Appendix B has a few examples of discoveries that others have made about their leisure while doing this exercise.)

I need to:
do things on my own ❑
be physically active ❑
be totally involved in something ❑
have others around ❑
do something meaningful to me ❑
try something that is hard for me ❑
keep busy ❑
do lots of different things ❑
relax and take it easy ❑
do something different from work or school ❑
be entertained ❑
entertain others ❑
be able to do what I want ❑
be in attractive surroundings ❑
make and carry out plans ❑
be creative ❑
feel pure pleasure ❑
think and be stimulated mentally ❑
make or design things ❑
share interests with others ❑
make other people feel good ❑
have an adventure ❑
have fun ❑
be spiritually satisfied ❑
try out new things ❑
dream ❑
be peaceful ❑

be spontaneous ❑
try my own methods of doing things ❑
laugh and enjoy ❑
compete with others ❑
be respected ❑
have a sense of purpose ❑
feel a sense of accomplishment and ability ❑
be with friends ❑
push myself to do better ❑
feel confident ❑
be outdoors and enjoy nature ❑
play ❑
be involved in sports ❑
meet new people ❑
be with groups ❑
develop a relationship with another person ❑
make use of my skills ❑
improve my skills ❑
learn new skills ❑
have a hobby ❑
get approval from others ❑
work with my hands ❑
fix things ❑
have something to show for my efforts ❑
do projects with others ❑
Other (please list)

You have identified the needs that you feel are important to you in leisure.

(e) ***What are my priorities?***

Instructions:

List below the three needs that you feel are most important to you in your leisure. List them in order of priority (that is, #1 is of greatest importance, and so on.) Then write them in the spaces on this page. For each, describe how you are meeting that need right now. If you are not, describe what's stopping you and what you could do to get that need met.

(1) Need:

How it is being met through my leisure:

(2) Need:

How it is being met through my leisure:

(3) Need:

How it is being met through my leisure:

This is a good point at which to have a group discussion about leisure discoveries, and to make note of these comments on the flip-chart paper. Group members can ask themselves questions such as: "How did I feel while I was doing the exercise?" and "What did I learn from doing the exercise?" The answers help the group to begin to see the unique role of leisure in life. (See Appendix B for discoveries that others have made.)

Personal Notes:

STEP 2. A Dream is a Wish

Purpose: To help the person being supported to express his or her wishes and dreams and to allow the group to dream together, developing a collective vision with the person being supported.

Discussion:

Dreams are what keep us going. Without them, we would miss out on an extremely important part of life. Many people with disabilities have not had the opportunity to dream aloud or share their dreams with their friends. Sometimes, they are discouraged from doing so because it is said that it only leads to false and unrealistic expectations. However, dreaming is a crucial initial stage in the process of developing a community and network of friends for people. It is also simply part of human nature and as such should be encouraged. Because the dreaming process specifically requires that the dreamer be as "unrealistic" as need be, the problem of false expectations is not a relevant one here. Dreams are to be held onto, whether or not they will be achieved.

The idea of this exercise is to dream together as a group. What does the person in need of support have as a dream? How can the group help the person to dream? How can the group dream together with the person?

Many people with disabilities have asked, "How do you dream?" because they have been denied experiences that would help them to know how. Labelled people often simply have no knowledge of things to dream for. Barb Goode (a self-advocate from British Columbia) says that dreams for people with disabilities are still often seen as unrealistic (personal correspondence, winter, 1988).

The first step to helping someone to dream is to make sure that we are not judging that person's dreams and wishes. The group must hear all the dreams. Any judgement or questioning on the part of a support person takes power out of the hands of the labelled person.

The group must also realize that because this is a sensitive vision developed **with** a person, not necessarily **by** her or him, it will have to be tested out, tried and re-envisioned as the supported individual becomes increasingly able to articulate his or her **own** vision. Thus, the vision developed here must not be seen as **the** vision for the supported individual, but as a collection of dreams by a support group about that person. This envisioning process is important because it gives **the group** dreams to hold onto with respect to the individual. However, the circled person will be the one ultimately responsible for taking the group towards her or his dreams.

Notes:

The circled person must be supported by a friend or advocate in answering the questions.

Dreaming
Instructions:

The person in need of support, as the central member of the group, takes part by stating desires and feelings about what others are saying, as well as by stating her or his dreams before, during, and after others state theirs.

Each member of the group tells a dream they have about the circled person's future life, whether it is related to leisure or not. Sometimes, a person needs or wants something else more than leisure, and that (for example, a job) might make leisure more possible. If this is the case, the group will need to be aware of it, in order to plan that the leisure and relationship connections do happen as well. Whatever the dreams, the circled person is invited to comment throughout the process.

Think of *how* the person who needs support will be involved in the process. Think also of what the group will need to do to keep everyone involved?

Dream by answering questions like:

What do I **want**?

What do I **wish** for?

What would make life **just great** for me?

STEP 3. Difficulties in Achieving the Dreams

Purpose: To understand clearly the challenges to leisure participation for the person who is being supported by the group.

Discussion:

Sometimes, something gets in the way of our getting what we want. This section is about the difficulties that have to be overcome to achieve our dreams.

There are many difficulties in achieving leisure and friendship for most people. But for someone with a disability, there are additional problems to solve.

We need to talk about difficulties because we need to think about how much control someone truly has over their leisure. For example, if someone is living on social assistance, how can she or he afford to do the leisure activities many of us take for granted, like going out to a movie?

Notes:

It is important to remember that people often prefer to talk about immovable barriers to leisure because this so easily leads to discussions of quick fix solutions rather than creative problem solving. The group will need to focus on challenges that can be met if they are understood. Think about challenges as existing because we have cast people into socially inferior roles. The group must be able to do this without thinking of the person or disability as the problem.

In this exercise, thinking creatively means thinking about **change**. To do this, it will be important to be open to the idea that not all challenges can be met at once for every person. We have to be able to list all the challenges and then deal with them one by one.
(See Appendix C for a comprehensive list of challenges for people with disabilities who are seeking leisure. Again, as with the other lists, this should be used as a resource only, since the group members will come up with their own useful list.)

Instructions:

Make sure that the person being supported has an opportunity to talk about personal difficulties in leisure, and insist that there is someone present who can help the person to talk about this, someone who knows the person well.

As a group, think of and say aloud the challenges that are personally experienced by the circled person in leisure and friendship.

A list of these statements can be made and posted on the wall. These will be used later when the group discusses what kind of support the person will need to participate in leisure.

Challenges:

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STEP 4. How Important is Friendship?

Purpose: These exercises allow the group to think about the importance of friendships.

Discussion:

Friendships are extremely important because, along with family, they make us feel accepted and that we belong. Many of the reasons why friends are important are the same for anyone, but people who have been clients of human services have a specific need for freely given, reciprocal friendship because of their particular situations of segregation and resulting relationship gaps.

Notes:

Family members and close friends who are participating in this experience can be helpful here in two ways. First, they can express why it is important to them to help the person being supported to have friendships. Second, they can support the person to speak for him/herself.

All members of the support group must be careful not to speak for the person. Sometimes, this is a challenge, but it's been found that even those people with the most challenging needs have very definite ways of communicating desires, needs, likes, and dislikes, when they have someone who will listen, particularly a trusted family member or close friend.

Friendships are important to all of us, and they do a great deal for us. Therefore, the first part (a) allows you to think about friendship and relationships generally before (b) thinking about the issue related specifically to the circled person.

(a) ***What is the importance of friendships and other accepting relationships in life?***

Instructions:

Each member of the group should do this part alone before sharing it with the rest of the group. The person being supported should get whatever help is required to do this exercise alone as well. For example, the questions can be put on tape and the individual can answer on tape if he or she does not write. If the person cannot do the exercise alone, then someone from the group can help.

Answer the following:

(1) What is a friend?

(2) What do friendships mean to me?

(3) What is the connection for me between my friendships and my leisure and recreation?

(4) How do my friendships lead to other good things in my life?

Now share these personal thoughts with the rest of the group.

(b) ***Discussing friendships together***

Instructions:

Now, as a group, discuss the importance of friendships and other relationships, for everyone, including people who have disabilities or who have been rejected in the past. Someone can write the important points from the discussion on another piece of paper and put it up on the wall. (Appendix E lists some reasons why friendships are important for people with disabilities.)

STEP 5. Leisure and Companionship: Connections

Purpose: To examine how leisure and relationships are interconnected. This step allows everyone in the group to see more clearly the connections between some kinds of leisure and relationships.

Discussion:

People often choose to participate in a leisure experience to be with certain others rather than simply for the benefits of the particular activity (Gunn, 1982). As examples, think about a few typical leisure involvements, such as eating in a restaurant or going to a movie. They are not activities that most people choose to do alone. Even if we are willing to take part alone, we often *prefer* to participate with a companion.

(a) *Leisure equals Pleasure*

Instructions:

Look back to 1(b) and (c) at the beginning of this manual to remember your group's ideas about leisure.

Now, each member of the group lists aloud two or three leisure experiences they care most about and like the best. The group can write these down on a flipchart. As a group, circle any experiences that have involved a friend or other person participating with you. You can also write your personal experiences below.

Personal Notes:
My own experiences:

Have a group discussion about how the leisure experience is associated with relationships with other people.

Now we can see more clearly the connections between friendship and leisure, and we can also see how much success we might have in linking ourselves or someone else to a natural community network.

(b) *What are the connections between leisure and friendship?*

Instructions:

Add to this list as a group, making it as long as possible.
In leisure, we:

- meet new people
- confirm old friendships
- get better acquainted
- grow to understand ourselves and others
- learn new skills from friends
- dare to try something new because of a friend
- have more fun because we are with someone we care about
- become more confident because we feel we can do something and we have someone cheering us on
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STEP 6. Overcoming the Difficulties in Leisure and Friendship

Purpose: To have many options for the group as a whole to choose from.

Discussion:

Much of leisure does not happen in isolation. It happens within communities, neighbourhoods, groups, clubs, parties, associations, and so on. So, one way to help someone become involved in leisure is to begin thinking beyond "programs" and classes as a way to meet leisure needs and to look at all the ways in which people are involved in leisure in our community.

Notes:

Ensure that the list generated is comprehensive and reflects what this group's particular community has to offer. There should be at least 50-60 ideas on the list and it should probably contain mostly those ideas that will be useful to the person in need of support. This exercise requires that the group take no more than 10-12 minutes to think of ideas. Thus, there is little time to discuss them. The greater the number of suggestions to choose from, the more likely it is that the very best ones will be chosen.

Focus on ideas that involve groups of people and thus are good places for friendships to begin. All group members should be careful not to pre-judge any activity or organization before it has been considered by the circled person. Groups and activities are usually chosen based on the values of the chooser. These values may not be agreed upon by every member of the group.

Instructions:

Look at all the wall paper you have produced. Now you can see your group's thoughts about leisure and friendship.

Keeping these ideas in mind, list on a new sheet all the places, events, and organizations in which you can experience leisure in your community.

Where I experience leisure in my community (here are some ideas to help you begin):

- the park
- YWCA/YMCA/YMHA/YWHA
- churches/synagogues/halls of worship/choirs
- radio-controlled car club
- Legion
- Junior Achievement
- Girl Guides/Pathfinders
- Minor League Baseball
- Oldtimers' hockey
- Ukrainian community centre
- continuing/adult education classes
- drama club

Continue the list and make it as long and as specific as possible. Include ideas about where group members might find relevant information about community activities. (Appendix F contains a long list that was generated in one community. Your list will be unique to yours.)

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STEP 7. Planning

Purpose: To create a useful plan to help the person being supported enrich her or his life as soon as possible.

Discussion:

We have looked at leisure, friendships, and connections between the two. We have also looked at some places, events, and organizations where leisure experiences happen.

Some people have said that they cannot plan for leisure because their lives are so busy. It seems that when people have lots of relationships and are very busy with others, planning just gets in the way and is often impossible. So the person being supported will probably not need a plan or planners once he or she is deeply involved and connected in leisure and relationships.

Planning should not be something that gets in the way and should only be used as needed. Not everyone will need or want to have a written leisure plan.

Notes:

The planning process should only occur with the presence of the circled person and his or her family and friends. Most important, there should be at least one person present who knows and is trusted by the person being supported.

The leisure plan should also involve *all* the other participants in the group. Everyone's input is important. However, it is crucial that the person with a disability be the *most involved* to ensure that the plan is relevant. No plan should be made unless the supported person is present and included as actively as possible. The planning process takes three to four hours. If the group's meetings are to take place on more than one day, it would be a good idea to break them up at this point — that is, after the reflection exercises and before the planning process. It is important to have all the information recorded, whether on big sheets of paper or otherwise, so they can be used in future plans, and to adapt and change the plan as needed.

Instructions:

Complete each item as a group, by identifying all the factors suggested below. Make sure that everybody works together and contributes to the information.

Use the spaces below for keeping a personal record.

(1) List the kinds of things the circled person likes and dislikes.

(2) List who is involved in her or his life.

(3) Draw the circles of people involved and/or previously involved in his or her life.

(4) List the kinds of leisure she or he takes part in.

(5) List the kinds of leisure he or she would like to take part in.

(6) Make note of those whom she or he would like to have participate in leisure experiences.

(7) Identify how this companion/connector person might receive support from the group.

(8) List any supports the circled person needs. (See Appendix G for examples of typical supports that are sometimes required.)

(9) Identify what other needs the supported person has related to leisure and friendships.

Note: we do not ever meet all our needs at one time. Try to talk about what the most pressing needs are using the list in 1(d)

STEP 8. Generating Realistic Options and Taking Action!

Purpose: To ensure that the group has a path to follow for future meetings and that group members have distinct tasks.

Discussion:

Here, it will be important to go through the process one step at a time. A great number of ideas and suggestions will be generated, but if each question is answered, the group will end up with a complete plan, and will not become so muddled. The group members can encourage each other to follow the outline through to the end.

(a) *Generating leisure options*

Instructions:

Thinking about wishes and needs, discuss all the leisure options that would be possible for the person being supported. Think of clubs, associations, groups, and so on. Think as much about informal leisure (e.g., parties) as about formal leisure (hobby clubs). Refer to Section 6 for the ideas you thought of before, and select those that make sense to the circled individual at his/her age and stage in life. Help the person to choose, but make sure that nobody in the group is choosing **for** the person.

Looking at the list, ask:

(1) What natural networks exist in which the person being supported would like to become involved?

(2) What challenges will need to be overcome in this group's situation?

(3) What supports will the group need to ensure?

(b) *Deciding on a plan of action*

Instructions:

With the help of other group members, the circled person can answer the following questions:

(1) What would you like to try first?

(2) Do you need or want someone from the group to go with you the first time or on a regular basis? Who do you want this to be?

(3) As a group, discuss what role this support person (connector) will need to play in the situation.

(c) *Discussing other issues*

Some of these issues may or may not be relevant to the group's particular situation. Just deal with those that make sense for your group.

Instructions:

Answer the following questions. You may or may not want to make notes as the group works together, either here or on the flipchart pages.

(1) If the person being supported is not in need of a companion/connector, how will he or she be introduced to the activity and group?

(2) What will this person need to make sure the experience is a good one?

(3) What about getting to and from the place of activity? How will this be organized?

(4) If necessary, who will get in touch with the contact person at the location?

(5) Does someone in the group know someone else who is a member of the relevant organization or involved in the event in question? Could this person be asked to help the circled person get to know others (i.e., act as a connector)?

STEP 9. Changing and Adapting Roles

Discussion:

The group is going to need to plan for its future. Many groups come together with a lot of energy and commitment, but have trouble staying together in the face of a struggle or challenging problem. It is important for any group that is supporting an individual with a disability to develop strategies for dealing with each challenge as it arises. The group can plan now for its future.

Notes:

Make sure that at all times, the person being supported is involved in the process, that this person's desires, wishes, needs, and interests are at the heart of the decisions that are made. Safeguard this by ensuring that:

- someone who really cares about and understands the person is present, and
- the group consistently focuses on the circled person by asking questions.

Instructions:

Answer the following questions.

(1) What role will your group continue to play as the situation and needs change?

(2) Maybe the supported individual wants to try a few things before making a final decision or choice. How might this be achieved?

(3) What tasks will each member of the group take on?

(4) Who might be invited to become a new member of the group so that it is growing as needed?

STEP 10. Beyond the Plan

There should be a definite, solid, and concrete plan of action at the end of the process in this manual. It does not have to be a written plan, but it must be one that is centred on the individual who is in need of support, and for that the group will be responsible. It should include the following questions:

(1) what will happen?
(2) who will be responsible?
(3) where will it happen?
(4) how will it happen?
(5) why will it happen?

For example, the group might decide on a simple plan, or something far more complex. It is suggested that the individual be involved in something that interests her or him as soon as possible, and that the structures be put in place so that the person can begin to lead a richer life quickly.

In fact, we all know most of what is contained here. But we are able, through this process, to know what we mean by terms such as leisure and friendship, terms we really don't think about much during everyday life.

NEXT STEPS:

Schedule a follow-up meeting date for the group to continue the support and make sure her/his life is in fact increasingly rich, full, and meaningful. At the next meeting:

(1) continue to think of ideas and to problem-solve together

(2) be prepared to continue the support without continuing the planning.

People with disabilities already have too many planners and plans in their lives. The sooner the group can leave "the plan" and move on, the better it will undoubtedly be for everyone involved. It is far more essential to deal with the matter of helping connect someone to the life of their community than it is to write out a

plan of how to go about it. This help or support should be flexible and involve only what is required by the individual. (For examples of certain kinds of support, see Appendix G.)

Always look for signs that the nature of support can change because the individual is actively involved in initiating and pursuing personal leisure interests and is connected to others who care to participate with and include him or her. This will not happen quickly, but will take time as people become connected in their communities and can become active participants in leisure that is personally meaningful and fulfilling.

If we want to help persons with a disability become rooted in their communities, we are required to find ways to help them meet and become friends with active and involved community members. Leisure experiences and opportunities provide some of the ways in which this can happen since it is in the community—in community associations, events, organizations, and groups—that jobs are created and located, that recreation and leisure are found, that multiple friendships are made, and that the rights of people with disabilities will be safeguarded (McKnight, 1985).

This manual is both a process and a guide for individuals with disabilities and their support groups. Once you have completed the manual, both it and the group process become documents of what the individual and group have gone through together in developing an initial plan. To move beyond the plan, it will be necessary to leave this book behind and allow the group to develop a process for working and playing together that makes sense to the members.

The individual and her or his support group should be able to continue the "connections" by helping the supported person meet community members who can in turn act as connectors to potential friends and different leisure experiences. These methods will always come from creative thinking and will flow from the commitment to help someone become connected with their community, thus strengthening both the individual and the community. It is our hope that this manual will help our readers develop such connections and perhaps make the lives of some a little richer.

Appendix A

What does leisure mean to me?

Leisure is:

stimulating
underrated in our culture
fulfilling
diverse
relaxing
enjoyable
refreshing
creative
necessary
solitary
experimental
pleasurable
valuable
restful
active
fun
rewarding
spontaneous
interesting
simple
priceless
entertaining
self-fulfilling
social
voluntary
cheap
hard to describe
educational
ego boosting
revitalizing
being with people
feeling good about myself
creating a balance in my life
escaping
learning
feeling good
relaxing with friends
having good times

being by myself
being free
being happy
being in my own little world
without obligation
family
the freedom to choose
the freedom to pursue
personal development
play
a break
reflection
friends/relationships
the absence of pressure
solitude
change
laughter
involvement
without mental stress
interaction
community
a way to satisfy and relieve pressure
different from routine
not demanding on my time
dependent on the mood I'm in
time to meditate
my choice
opportunity

Appendix B

Leisure Discoveries

1. Different definers for leisure are interconnected.
2. Leisure is related to my whole life — if I feel good about myself in one area, I will in leisure.
3. I have to separate work from leisure.
4. My leisure isn't quite as much a part of my life as I thought.
5. Leisure is often shared and compromised.
6. We don't take the time to reflect on what our leisure needs are.
7. Some things that one wouldn't call leisure may be leisure to others.
8. Leisure is a state of mind.
9. I don't get much leisure.
10. It's something I do for me.
11. I meet many of the same needs in work and in leisure.
12. It's a high priority.

Appendix C

Challenges in Leisure for People with Disabilities*

1. The person is often seen as the problem.

2. People are denied basic human rights.

3. People do not have unpaid, non-legal advocates.

4. People often have limited income. Being poor means more health problems and more isolation. It means you can not dress as well or eat as well as others in your community. It is more difficult to keep your life running smoothly, and thus leisure becomes harder to find and hold onto.

5. People who work in human services and recreation are more often programmers than facilitators. Staff people often see people with handicaps as "clients," not as **people** who have rights and who need caring relationships.

6. Our communities are still inaccessible in many ways to people with disabilities. We have made some strides with physical access, but attitudinal and financial access are often still out of reach. Many community recreation buildings and parks remain inaccessible physically as well.

7. Lack of affordable, accessible, and integrated transportation services makes participation difficult.

8. People are often denied membership in community clubs and organizations.

9. People spend very little time in community places.

10. People have few or no peer friends with whom to participate.

11. People who have been segregated and isolated are often unsure of what to expect in social settings.

12. Non-labelled community members are often unsure of what to expect as well since it is rare that they will have met an individual with a disability and are thus not accepting of differences.

* Adapted from an initial list by Judith McGill, 1988.

Appendix D

Challenges in Friendship for People with Labels (in addition to challenges in Appendix C):

1. People who work in human services rarely have an actual friendship or committed personal relationship with a labelled person.

2. People have been set apart, isolated, and congregated with other labelled people. This means they have little experience with making and keeping friends. Friendship is something we learn in the social environment. If people are kept from this environment, they lose the opportunity to learn.

3. With only a few friendships with non-labelled people, it becomes difficult to meet and get to know other potential friends.

4. People are often supervised or constantly accompanied by a companion, so that others find it difficult to get to know them:

   > Olivier is always accompanied by someone, whether it is a paid facilitator or a family member. At lunch he is accompanied by someone to go to the cafeteria to "hang out." He is accompanied during classes and after school. I believe that this has become the major stumbling block to Olivier making friends with his peers. Seventeen-year-olds do not want adults "hanging around" with them. It becomes a vicious circle. Until Olivier builds close relationships with his peers he will need to be accompanied by adults, but while he is being accompanied by adults he is not likely to build close relationships with his peers. (Savard, 1988)

5. Adults with labels lead segregated and isolated lifestyles. Many live in group homes, or like situations, attend sheltered workshops, and participate in segregated leisure such as "special bowling." Their time spent in typical community places with typical citizens is limited. This is a challenge in both leisure and friendship facilitation.

6. People who are labelled are usually considered incapable of having intimate, loving partnerships or even needing them; and thus friendships are not encouraged by support persons.

For example, we know of one situation in a group home where telephone messages were not passed on. This raises the concern that perhaps friendship is not taken seriously by some of the staff in residential service settings.

7. Human service workers often consider themselves as the primary friends of people with disabilities, sometimes making it difficult for others to get to know them.

8. Sometimes, people's lack of experience and support results in the neglect of personal hygiene. This can be a barrier to the formation of friendships. It is always easier to be close to someone who smells terrific and looks good.

Appendix E

The Importance of Friendships (Summarized from "Friends Circle to Save a Life," by Robert Perske, **entourage**, Volume 3, Number 1, Winter 1988.)

Friends help us move beyond human service goals. Friends provide us with a myriad of options that could never be received in a program.

Friends help us rehearse adult roles.

Friends serve as fresh role models.

Good friendships are a mystery.

Good friendships are attractive. Others watch them with great interest.

Friendships generate their own energy.

Friendships become a haven from stress.

Friendships are reciprocal. Both parties receive some kind of enrichment from the relationship.

If a person is breathing, he or she needs a friend. So say many advocates with a special interest in friendships.

Friends can demystify strange behaviour.

Human service workers cannot program friendships. They can, however, set up frameworks in which friendships can happen.

Every friendship is unique and unrepeatable.

We can learn a great deal from good friendships. A good friendship can become a "living document" through which we can form new values for our field.

Appendix F

Community Leisure Opportunities

(This list was generated in Dryden, Ontario, by volunteers supporting individuals with disabilities in leisure)

Dart clubs
Curling clubs
Friendship Centres
Knights of Columbus
Bingos
Socials
Volunteering
Bowling Leagues
Church Groups: e.g., women's or youth groups
Kinsmen clubs
Rotaract (BBQ, Polaroid Party, Dances, Canvassing)
Rotary clubs
High School Clubs
Alcoholics Anonymous
Women's Institute
4H Clubs
Arrive Alive
Skiing-Nordic and Alpine Clubs
Skating Clubs
Hockey Leagues
Baseball Leagues
Soccer Leagues
Aerobic Classes
Brownies/Guides/Pathfinders
Boyscouts/Cubs/Cadets
Bible study
Night classes
Sewing and craft courses
Music lessons
Santa Claus parade
Snowmobile clubs
Pancake breakfasts
Bars (Moose, Legion, PI, Central)
Dances (Spring frolic, baseball, high school)
Weddings
Funerals
Playgrounds
Beaches

Singles clubs
Single parents clubs
Teas and bazaars
Sleighrides
Tournaments, bonspiels (i.e., horseshoes, baseball, curling)
Yacht clubs — sailing courses, regattas
Art lessons
Weight clubs
Pool and fitness centres--aerobics, weights, swimming, squash, racquetball
Vermilion Bay relay race
Hoshizaki House
Fall Fair
Parties, i.e., crystal, make-up, tupperware, plants, etc.
Camps — summer, language
Holidays
Visiting — friends, neighbours
Ice fishing
Camping
Casinos — Las Vegas Night
Friends of the Museum
Big Brothers/Big Sisters
TOPS and Weight Watchers
Senior Citizens Clubs/Complex
Theatres
Drive-in movies
Archer clubs
Doctor's office
Gymnastics
Broomball Leagues
Flying clubs
Model planes
Dog fanciers
Inventors
Fundraisers
Gun clubs
Card clubs, i.e., bridge
Volunteer Firefighters
Ham Radio
Red cross
Square Dances
Dance lessons (classical, ballroom, jazz, social)
Geneology
Library clubs
Go-getters

Dryden Entertainment Series
Roller skating
Serenaders
Choirs
Sunday school (attending or teaching)
Parish Council
Alter Guild
Baptism
Picnics
Hospital Auxiliary
Meals on Wheels
Golfing
Mini-golf
Restaurants and coffee shops
Horseshoe clubs
Lion's clubs
Foresters
Homeshows
Sports shows
Trade shows
Garage sales
Fish derbies
Antique car clubs
Off-roader
Conservation clubs
Horticultural society
Town council/local politics
Political Parties
Multicultural associations
Artist's societies
Badminton clubs
Edelweiss clubs
Cycle clubs
Barber shops
Clothing shops
bike stores
truck stops
Supermarkets
Bus stops
Babysitters
Ukrainian Hall
Coff Hall
Quilting Bees
Unions, i.e., Teacher's Associations
Saddle clubs

Chamber of commerce
Outsiders
Canoeing
Fish Fry
Kin Karnival
Skate-a-thon, walk-a-thon, etc.
Welcome wagon
Hairdressers
Bernier Day
Model Plane clubs
La Leche League

Appendix G

Different people have been supported in different ways to enjoy leisure and make friends. Here are are several stories to illustrate how supports can take place. These are not formulas. Each individual situation will dictate the type of supports required.*

(a) It was paid staff support workers who helped one man to understand that he could invite his co-workers to his house for pizza. He came to realize that he did not have to wait for an invitation to spend time with them. The integrated work situation provided the setting for relationships and leisure to happen, but it took staff support to create the impetus.

(b) It was a volunteer coordinator who first heard that Jim, a man with a mental handicap, wanted something interesting and absorbing to do. She was supposed to find him a "one-to-one." Instead, knowing how he loved hockey, she approached the Old-Timers' Hockey Team in their town. Jim wanted to be involved in hockey, even though he could not play, and he wanted a social life and friends. The volunteer coordinator realized that the support could come from the team members and a "buddy" was not required. The team took Jim on as manager and they helped him to do his job. The "connector" in this case was a volunteer coordinator. She now keeps in touch with Jim and the team and helps them problem solve. Jim is a full team member, participating in road trips and news photographs.

(c) One support group was able to help a young woman learn how to dress appropriately for her youth group. A member of the circle was also a member of the youth group. She took Theresa shopping and helped her pick out "cool" clothes. They picked out the "coolest" so that Theresa would really feel like she was a part of things. The next weekend, all the people in the youth group raved about the change in her appearance.

(d) A paid staff person helped a young man form his own bowling team so that he could play in the local recreational league. Sam loved it. He had been refusing to attend the "program," which took place every Saturday for all the people with

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* *Some of these stories (a,b,d) are real. The others are composites of stories told to the authors.*

handicaps in the community. Now with his own team, he would eagerly await his Monday night games. The staff person had supported Sam's wishes and desires and worked hard to make them come true. At the end of the season, Sam's team received the league award for the most improved team. A year later, when the supporter moved on to another job, Sam was required, for logistical reasons, to return to the segregated program, which he hated. This story illustrates how much impact one listening support person can make in someone's life. But it also shows how little the human service system can do to safeguard people's connections to their leisure and community participation.

(e) An agency volunteer formed a small support group of local teenagers for a young woman living in a neighbourhood group home. They gathered together for a meeting in Kris's living room one day after school. As the group made plans to do some things together with Kris, it became apparent to the volunteer that Kris would need support in the form of rule changes if she was to have enriched leisure and real friendships with these young people. She explained to the group that there was a rule stating that a staff person would have to be with Kris all the time when she was out. The group members decided that their first task as a support group was to get this changed. They never went to the mall or the park with a chaperone, and they saw no reason why this would be necessary for Kris. Their first form of support came in the form of meeting with the agency, with Kris present, to tell their story. Together with agency staff, they figured out an emergency procedure system that would ensure Kris's safety without requiring the ever-present adult.

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Canada's National Institute for the Study of Public Policy Affecting Persons with an Intellectual Impairment

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- to foster the exchange of ideas leading to new ways of thinking about persons with an intellectual impairment.

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